Making it better

20 January 2025

Craig Russell & Kate Fitzsimons

On behalf of the CRANE Database team

Overview

- Welcome and introductions (CR)

- 2024 Annual Report – key findings (KF)

- Shared learning relating to good practice and challenges (7 presenters)

- Q&A session (CR)

- CRANE Database developments (KF)

- CRANE update (CR)

- Finish by 12:00

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ADVANCING SURGICAL CARE

CRANE
CLEFT REGISTRY & AUDIT NETwork

Welcome & introductions
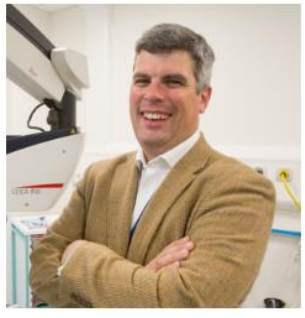
Craig Russell

Clinical Project Lead

Consultant Cleft, Plastic and Reconstructive Surgeon, NHS Greater Glasgow and Clyde

Jibby Medina

Programme Manager,

Clinical Effectiveness Unit, RCS

Kate Fitzsimons

Senior Research Fellow,
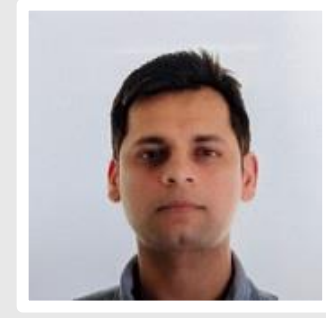
Clinical Effectiveness Unit, RCS

Sophie Butterworth

Clinical Research Fellow

Jan van der Meulen

Methodologist,

Clinical Effectiveness Unit, RCS

Professor of Clinical Epidemiologist, LSHTM

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Data Manager/Data Scientist,

Clinical Effectiveness Unit, RCS

2024 Annual Report

- Published December 2024
  - Key findings & recommendations
  - Registry information
  - Consent verification
  - 5-year outcomes
  - Development work
- Infographic
- Supplementary tables
- Outlier responses
- Local Action Plan
- Patient/carer version

CLEFT REGISTRY & AUDIT NEtwork

Promoting excellence in cleft care

Cleft Registry and Audit NEtwork Database
Part of the Clinical Effectiveness Unit, of the Royal College of Surgeons of England

2024 Annual Report
Results of the registry and audit for children born with a cleft in England, Wales, Northern Ireland and Scotland

On behalf of the Cleft Development Group

Annual Report 2024

CRANE is a national registry and clinical audit. It evaluates and reports on the delivery of cleft services to children born with a cleft lip and/or palate in England, Wales, Northern Ireland and Scotland. Registry information is presented for children born in 2021-2023 and audit outcomes at 5 years of age are presented for children born in 2015-2017.

Registry information

24,877 children have been registered, over the last 24 years, since 2000.

859 children were registered in 2023.

78% of babies with cleft lip were diagnosed antenatally, while 74% of babies with cleft palate alone were diagnosed within 24hrs of birth.

82% were referred to a cleft team within 24hrs of birth and 94% were contacted within 24hrs of referral.

Distribution of cleft type

CP	CL	UCLP	BCLP	SMCP	SMCP+CL
43%	26%	21%	9%	<2%	<1%

Soft palate (34%) Soft & hard palate (66%)

Key: Cleft palate (CP); Cleft lip (CL); Unilateral/bilateral cleft lip and palate (UCLP/BCLP); Submucous cleft palate (SMCP).

88% of families had a verified consent status, 85% consented and 3% declined consent.

Audit outcomes at 5 years of age

Body mass index
83% of children with a cleft had a healthy BMI. 3% were underweight, 9% were overweight and 5% were obese.

Dental health
62% of children with a cleft had no decayed, missing or filled teeth (dmft=0), compared to 77% of their non-cleft peers.

Facial growth
52% of children with a complete unilateral cleft lip and palate (UCLP) had scores reflecting good dental arch relationships.

Speech
57% of children with a cleft affecting the palate had speech comparable to their peers. Children with a cleft palate (CP) alone had better outcomes than those with a cleft affecting the lip and palate.

Psychology
82% of children with a cleft had 'Strengths and Difficulties' scores in the low/normal range, compared to 90% of their non-cleft peers. Furthermore, 92% of families were screened at least once before the target age of 6 years.

Development work

Deprivation according to postcode records
For the first time, postcodes were used to assign deprivation scores to 88% of CRANE-consented children born 2014-2023. We found that babies with a cleft were no more likely to live in the most deprived areas than babies born in the general population. However, the percentage of children with a cleft living in the most deprived quintile areas varied between Cleft Services from 11% to 47%.

Newborn Hearing Screening Programme (NHSP) data linkage
CRANE-consented children were linked to the NHSP at the individual-level to report on their diagnostic audiology assessments.
61% of children with a cleft had a diagnostic test:
1 in 4 had conductive hearing loss, and
1 in 25 had permanent hearing loss.

For further information visit www.CRANE-Database.org.uk 𝕏 @CRANE_News

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Alert/outlier tables: Early care

Cleft service alert and outlier status for data items **NOT** subject to the outlier policy (2021-2023 births). Data submitted to the CRANE Database by 1 July 2024 is included

Cleft Service	Robin Sequence	Consent verification	DATA COMPLETENESS					OUTCOMES				
			Gestational age	Birthweight	Diagnosis	Referral	Contact	Diagnosis of CL, UCLP & BCLP before birth	Diagnosis of CP <24hrs of birth	Diagnosis of CP <72hrs of birth	Referral <24hrs of birth	Contact <24hrs of referral
Newcastle					+•	- -	+•			-		
Leeds		+	++•	++•	+	+•	++•					
Liverpool	-•	++•	++	++		++•	+•		+		+	
Manchester		++•	+	+		++•	+•	+•			+	+•
Trent			++	++	+							++
West Midlands*	- -•	- -•	- -•	- -•	- -	- -•	- -•	-	++	+	+	- -•
Cleft Net East	-	-	- -	- -	-			- -				
North Thames		++•	- -•	- -•		++	- -•				-	- -•
Spires	-•		+	+			+	- -•				-•
South Wales	++		++•	++•								
South West			++•	++•	-		-					
Evelina London			++•	++•			++•					
Northern Ireland			++•	++•							- -•	- -•
Scotland		++	++•	++•	+	++		+	+			

Outlier status for previous year included

Table 1 of 2: Number (%) of CRANE-registered* children born in 2015-2017, according to consent status and Cleft Service
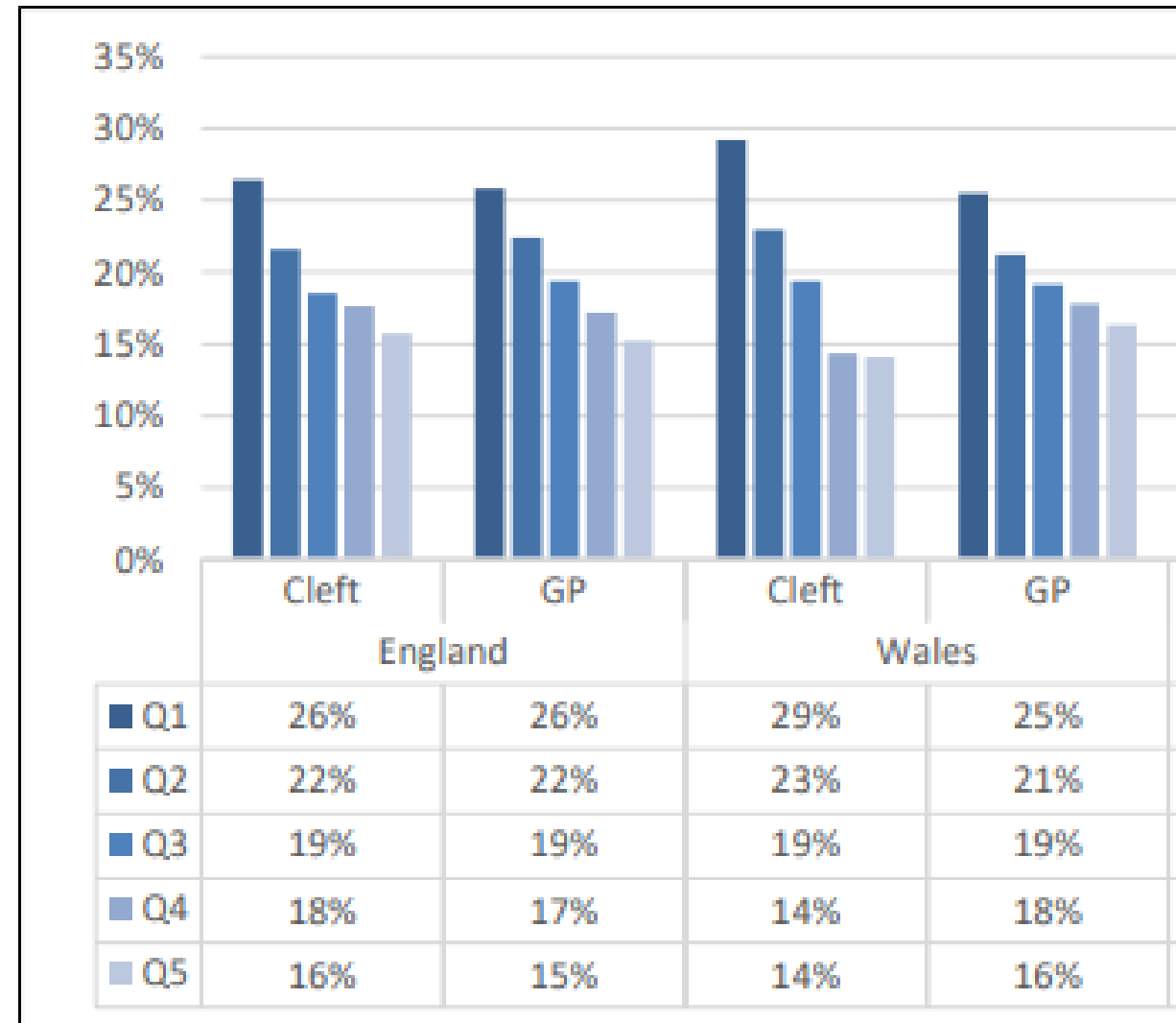
Cleft service	CRANE-registered children + non-registered children in Scotland	Consented		Declined		Total children verified	Awaiting verification		Not possible to verify		Outlier status**	2023 AR outlier status
	N	n	(%)	n	(%)	(%)	n	(%)	n	(%)		
Newcastle	168	161	95.8%	4	2.4%	98.2%	0	0.0%	3	1.8%	Positive outlier	Positive outlier
Leeds	179	178	99.4%	1	0.6%	100.0%	0	0.0%	0	0.0%	Positive outlier	Positive outlier
Liverpool	216	198	91.7%	3	1.4%	93.1%	10	4.6%	5	2.3%		
Manchester	202	180	89.1%	3	1.5%	90.6%	16	7.9%	3	1.5%		
Trent	283	253	89.4%	4	1.4%	90.8%	26	9.2%	0	0.0%		
West Midlands	397	320	80.6%	21	5.3%	85.9%	51	12.8%	5	1.3%	Negative alert	Negative outlier
Cleft Net East	218	190	87.2%	4	1.8%	89.0%	18	8.3%	6	2.8%		
North Thames	363	341	93.9%	4	1.1%	95.0%	15	4.1%	3	0.8%	Positive alert x2	Positive alert
Spires	290	249	85.9%	5	1.7%	87.6%	36	12.4%	0	0.0%		Negative alert
South Wales	100	92	92.0%	1	1.0%	93.0%	3	3.0%	4	4.0%		
South West	198	181	91.4%	1	0.5%	91.9%	14	7.1%	2	1.0%		
Evelina London	377	331	87.8%	23	6.1%	93.9%	9	2.4%	14	3.7%	Positive alert	
Northern Ireland	90	88	97.8%	0	0.0%	97.8%	1	1.1%	1	1.1%	Positive alert	
Scotland***	168	110	65.5%	0	0.0%	65.5%	55	32.7%	3	1.8%	Negative outlier	N/A
Total incl Scotland's non-registered cases	3,249	2,872	88.4%	74	2.3%	90.7%	254	7.8%	49	1.5%		
Total excl Scotland's non-registered cases	3,191	2,872	90.0%	74	2.3%	92.3%	199	6.2%	46	1.4%		

Cleft palate detection time by extent of cleft involvement
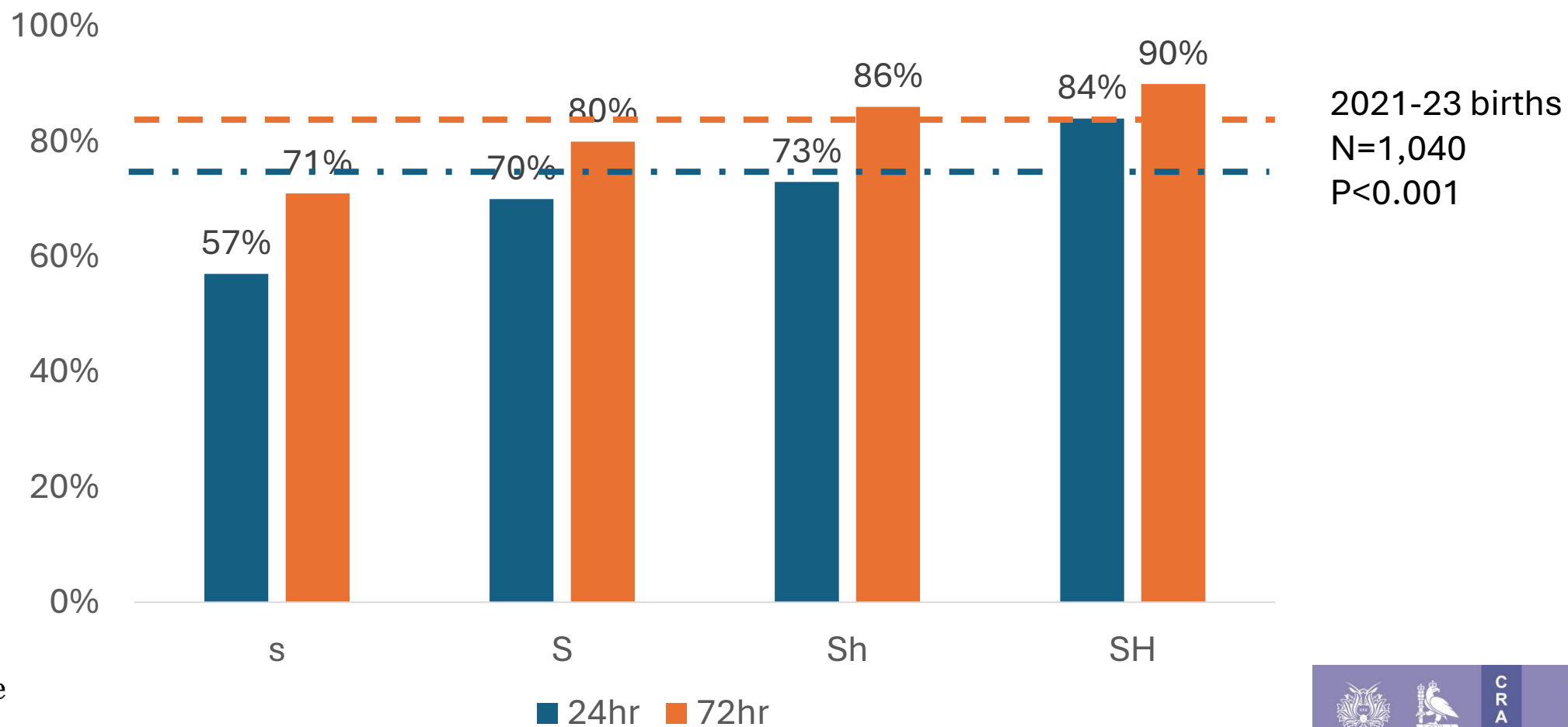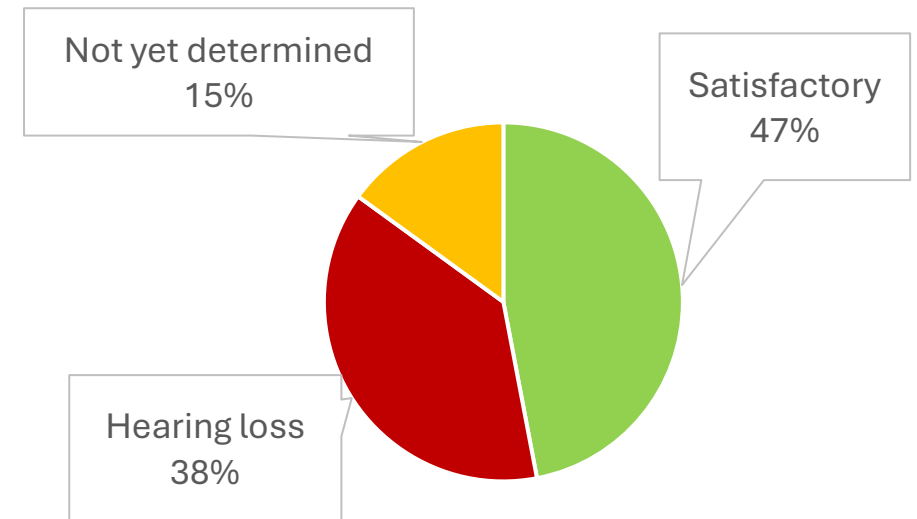
Development work: Socioeconomic deprivation

- Children with a cleft (2014-23 births) are no more likely to live in the most deprived quintile areas than babies in the general population.

	England		Wales	
	Cleft	GP	Cleft	GP
Q1	26%	26%	29%	25%
Q2	22%	22%	23%	21%
Q3	19%	19%	19%	19%
Q4	18%	17%	14%	18%
Q5	16%	15%	14%	16%

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Development work: Socioeconomic deprivation

- Children with a cleft (2014-23 births) are no more likely to live in the most deprived quintile areas than babies in the general population.

- % of children from the most deprived areas varied between Cleft Services (11%-47%).

- We know dental outcomes are strongly related to deprivation.

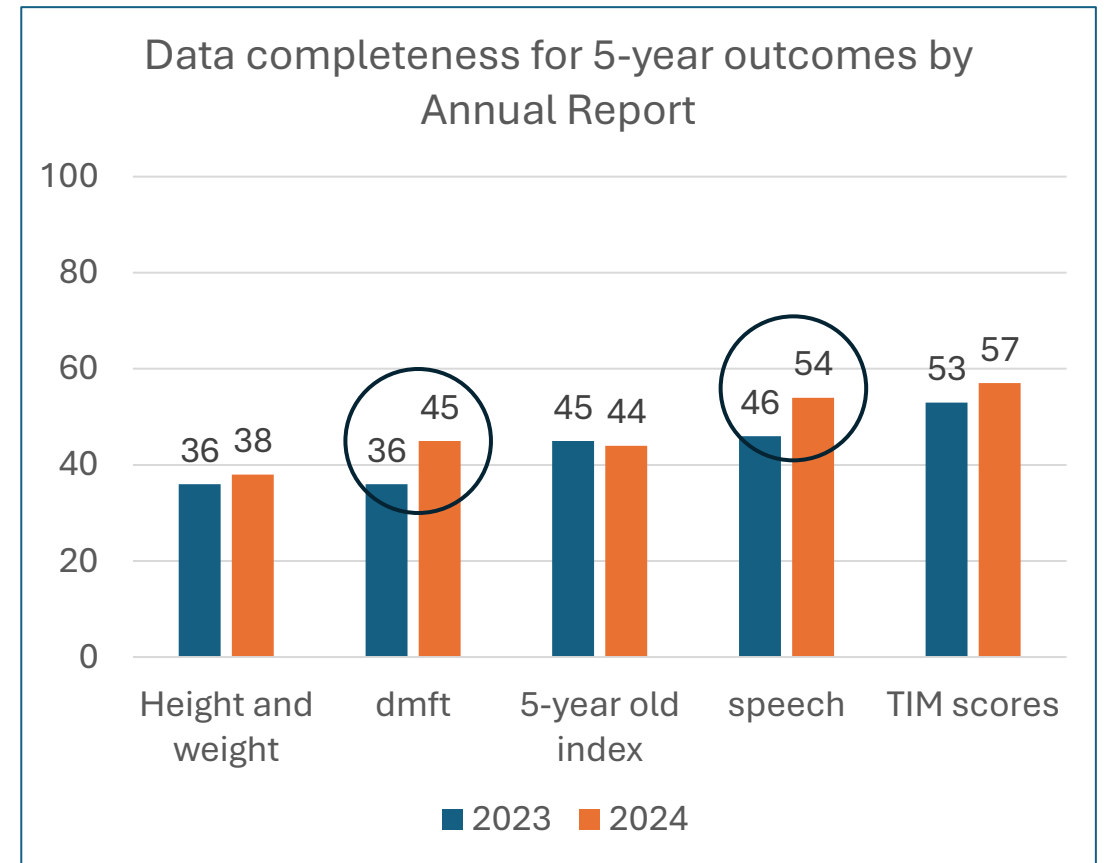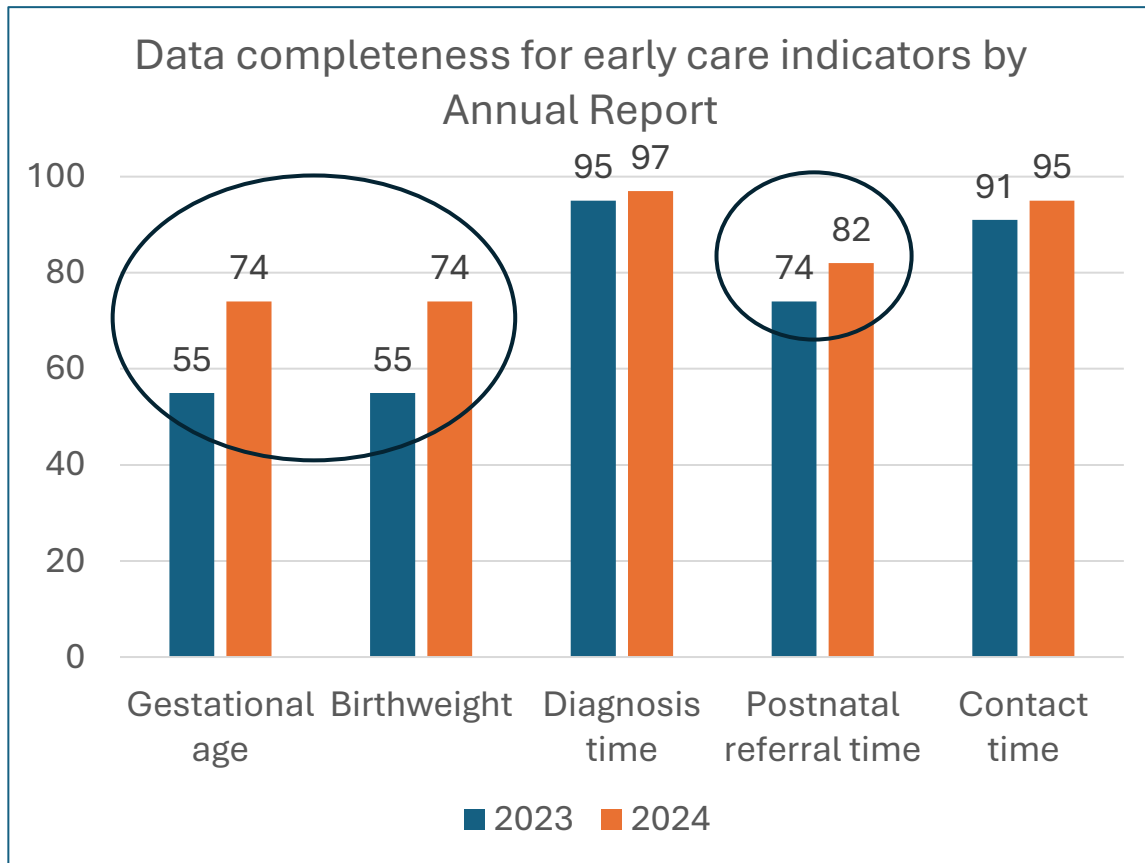- Risk-adjustment of outcomes should include IMD, based on postcode.
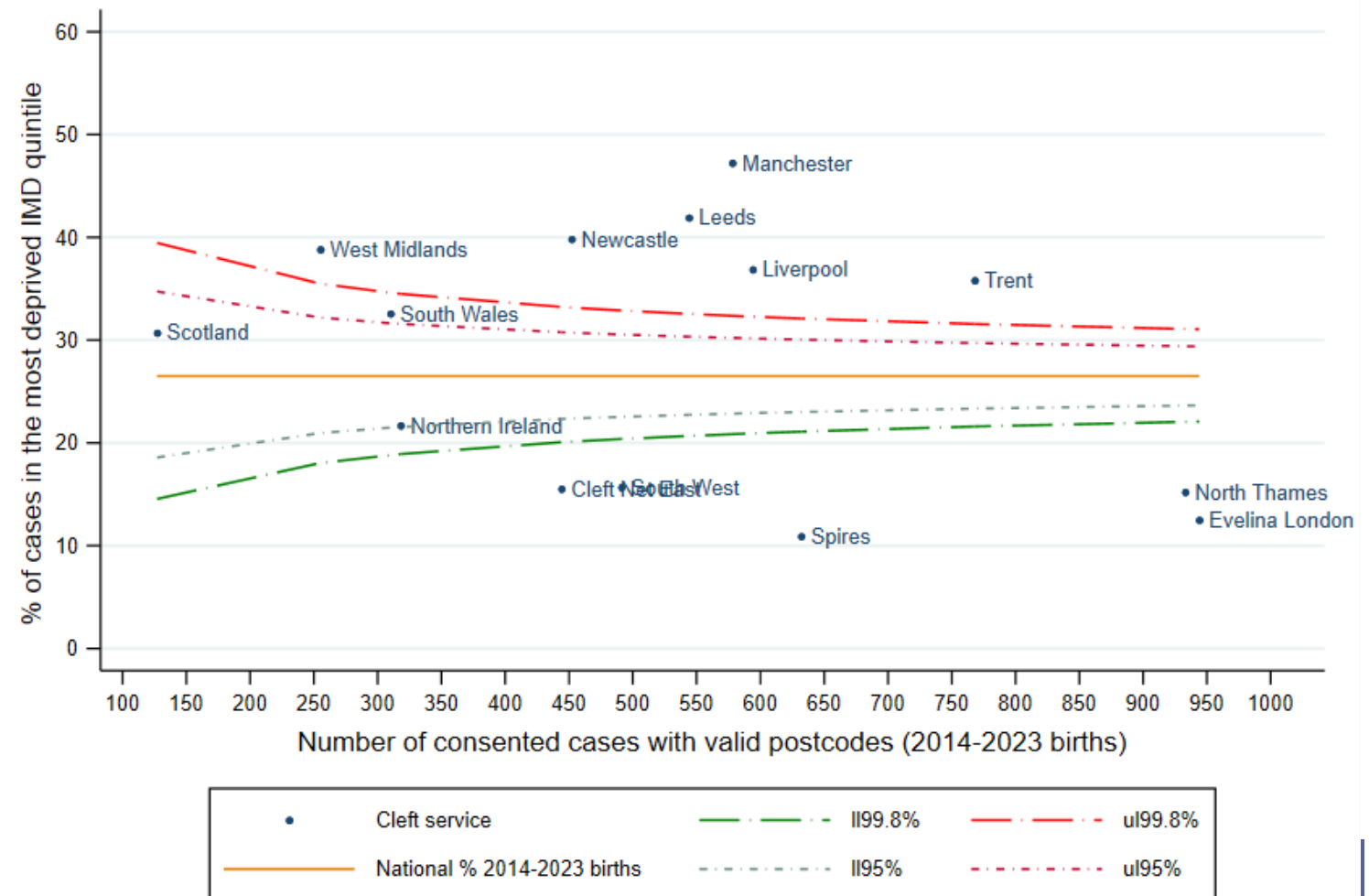
Note 1. Data from Wales, Scotland and Northern Ireland based on their country-specific deprivation measures.

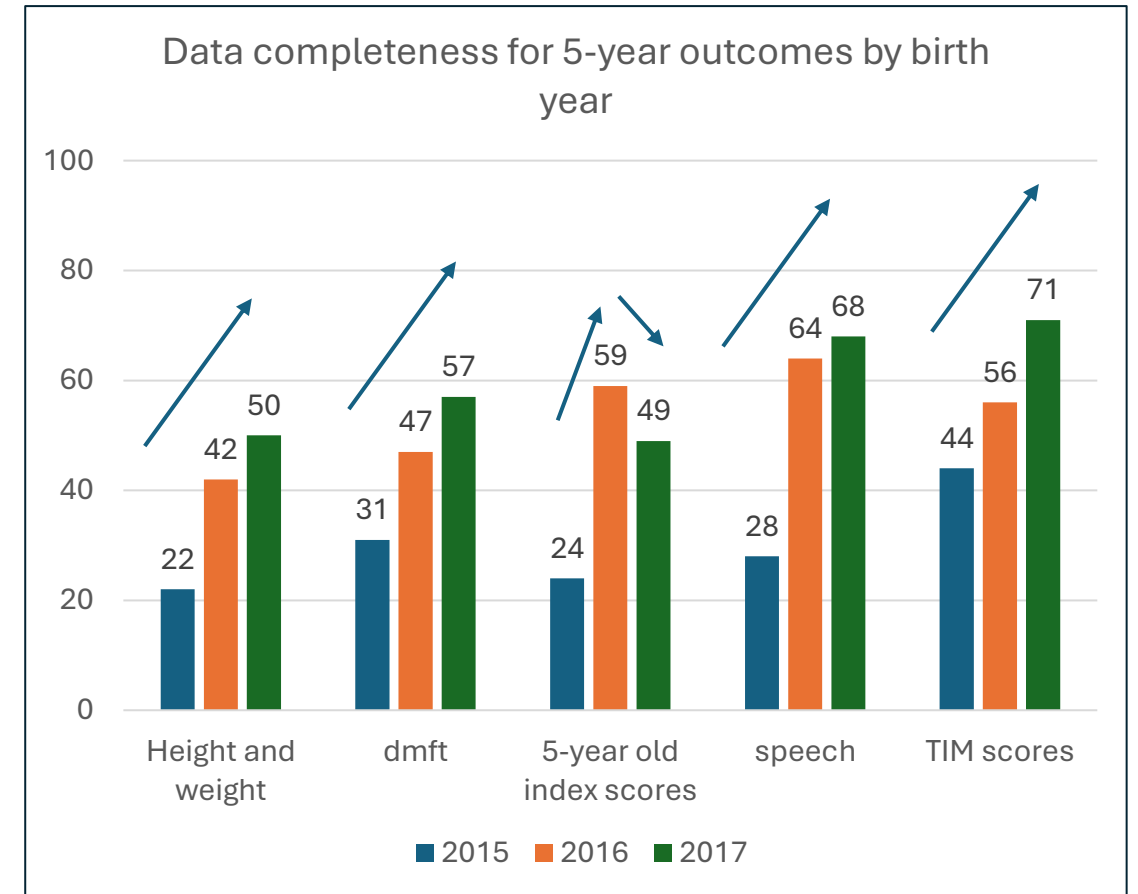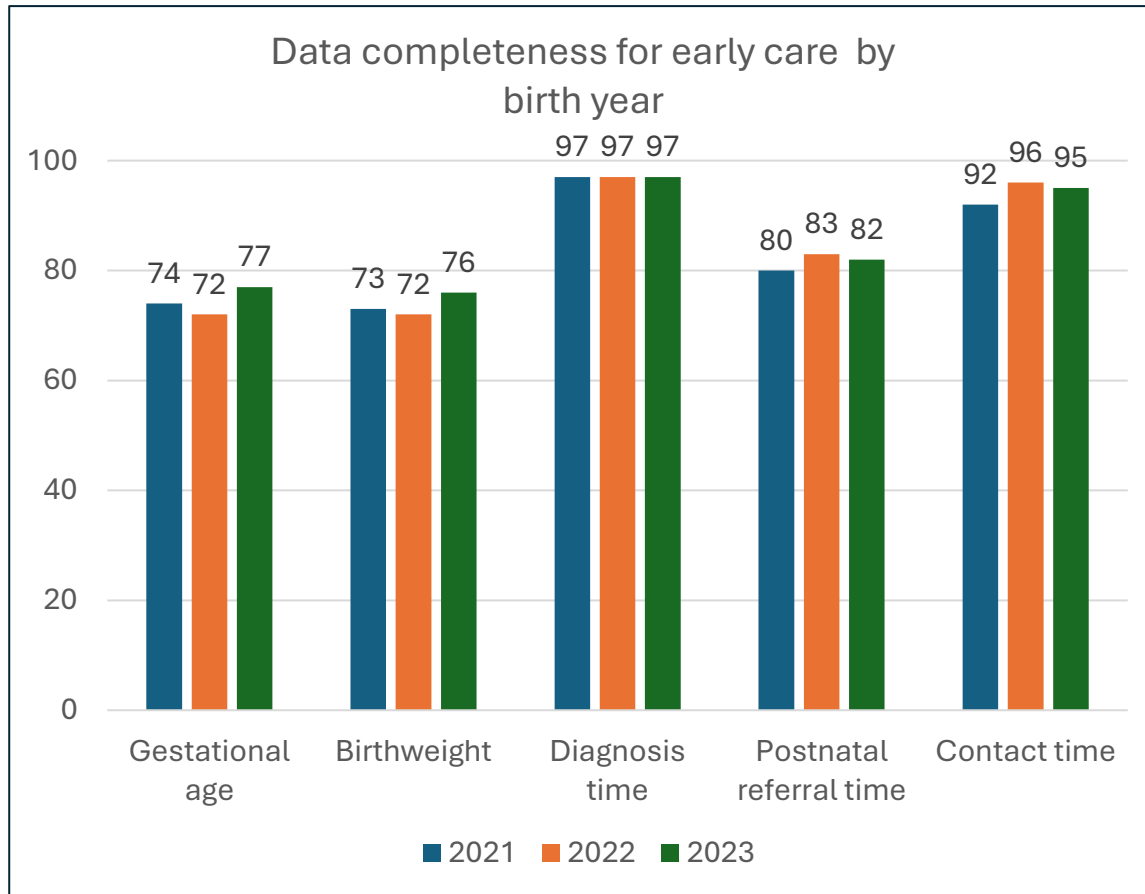# Development work: Hearing status

- 7,116 (61%) children with newborn hearing screen had diagnostic audiology assessment (2006-21 births)
    - 29% with CL
    - 72% with CP+/-L (benchmark is 100%)
- 3,351 (47%) had satisfactory hearing
- 2,721 (38%) had hearing loss identified
- 268 (4%) had permanent hearing loss
- 12% with clear response on newborn hearing screen had conductive loss identified at diagnostic assessment.

Not yet determined 15%

Satisfactory 47%

Hearing loss 38%

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Data completeness by year of birth

Data completeness for early care by birth year

	Gestational age	Birthweight	Diagnosis time	Postnatal referral time	Contact time
2021	74	73	97	80	92
2022	72	72	97	83	96
2023	77	76	97	82	95

Data completeness for 5-year outcomes by birth year

	Height and weight	dmft	5-year old index scores	speech	TIM scores
2015	22	31	24	28	44
2016	42	47	59	64	56
2017	50	57	49	68	71
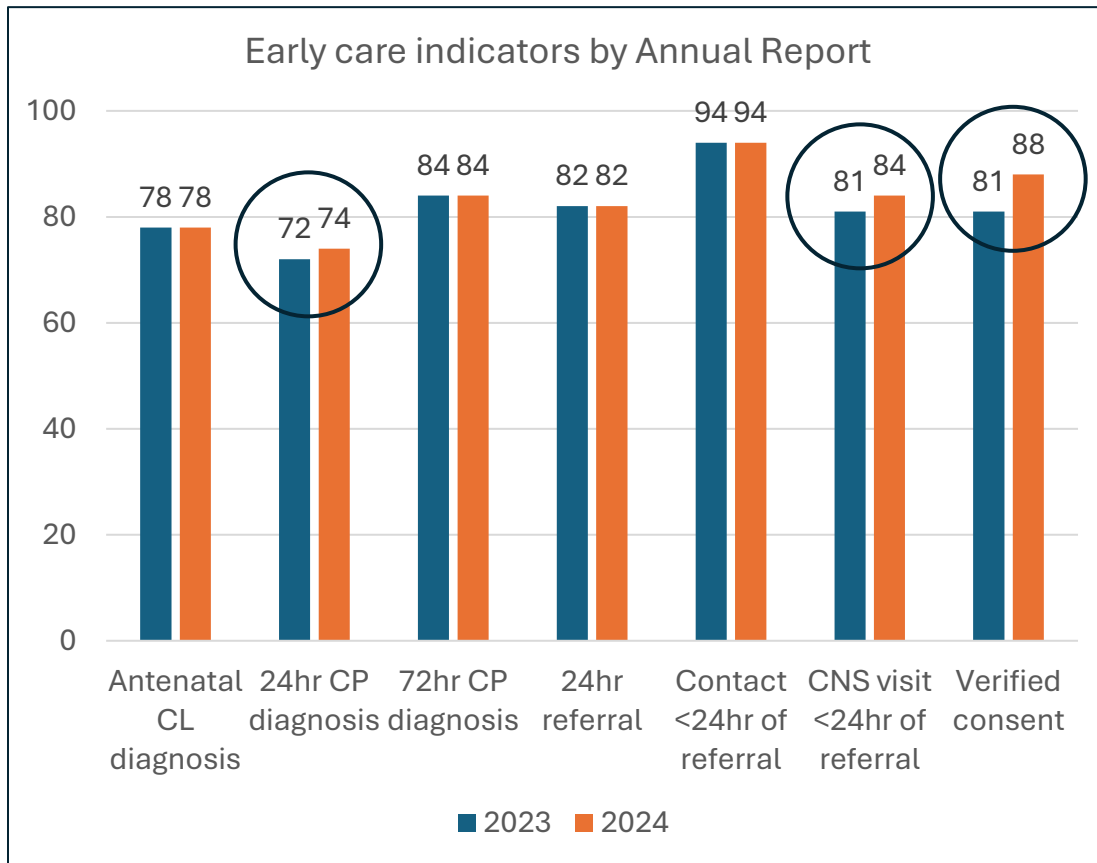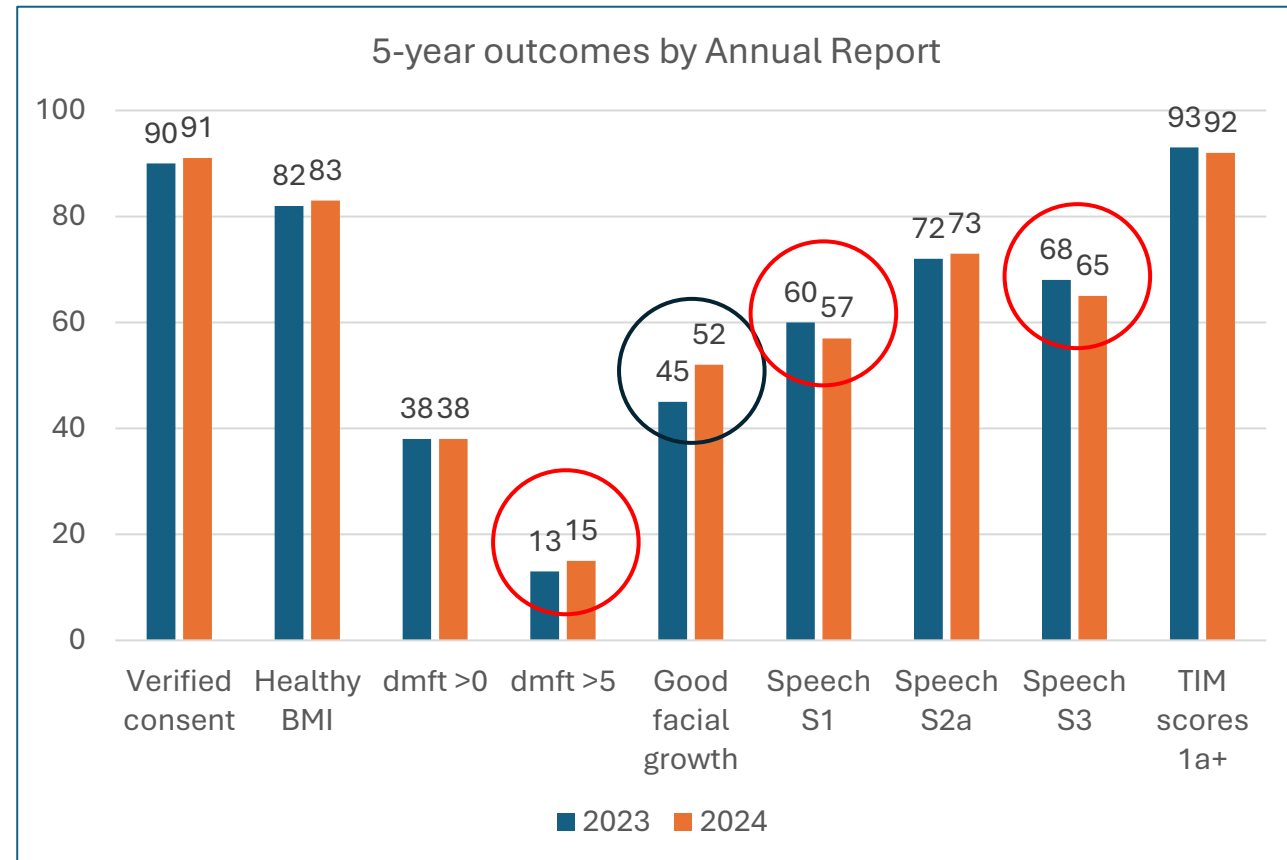
Learning from good practice and challenges relating to data submissions

Palate examination: identification of cleft palate in the newborn and infant

Alex Habel, Honorary Consultant Paediatrician GOSH
Helen McElroy, Consultant Neonatologist, Medway NHS

Quality improvement project at Medway

Implemented 2014

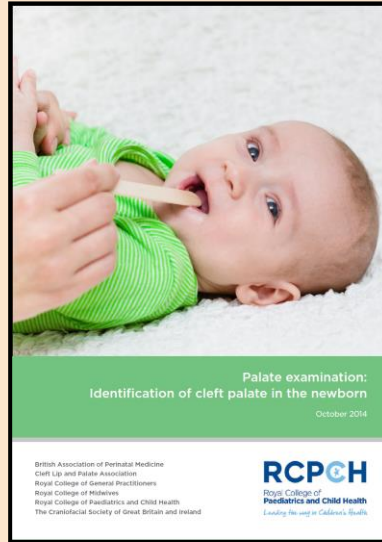Response to late diagnoses and RPCH Best Practice Guide

3 areas for PDSAs

Sustained improvement in timely diagnosis over 10 year period

Education

Guidance

Palate examination:
Identification of cleft palate in the newborn
October 2014

British Association of Perinatal Medicine
Cleft Lip and Palate Association
Royal College of General Practitioners
Royal College of Midwives
Royal College of Paediatrics and Child Health
The Craniofacial Society of Great Britain and Ireland

RCPCH
Royal College of
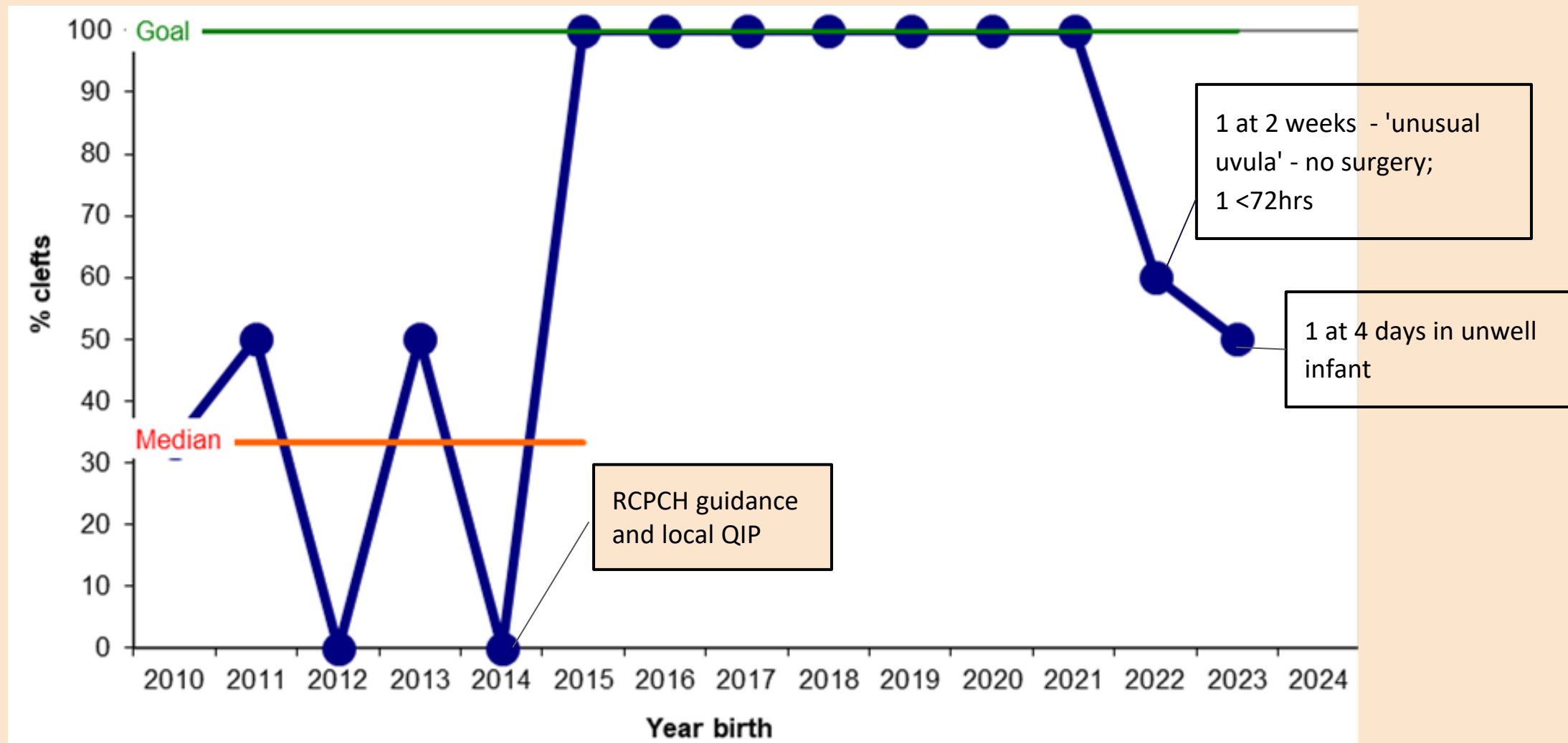Paediatrics and Child Health

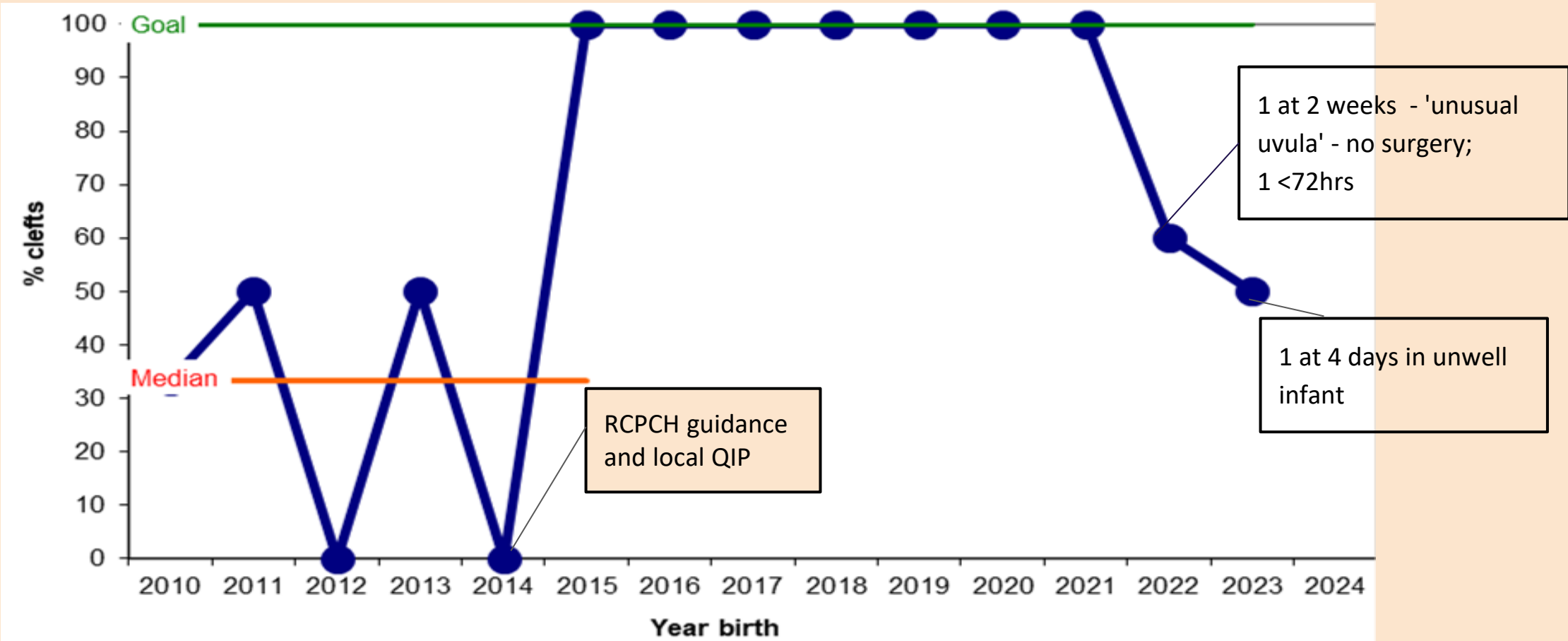# Practice

Early examination of palate repeated at NIPE

DATIX reporting and feedback on missed diagnosis

Monitoring outcomes

Regular NIPE teaching for midwives and residents

% cleft palate detected within 24hrs birth - Medway NHS FT

Annotations on chart:
- 1 at 2 weeks - 'unusual uvula' - no surgery; 1 <72hrs
- 1 at 4 days in unwell infant
- RCPCH guidance and local QIP

		2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024
Cleft services standard	<24hrs	33.3	50	0	50	0	100	100	100	100	100	100	100	60	50	
PHE NIPE standard	<72hrs	66.7	50	0	75	50	100	100	100	100	100	100	100	80	50	
	>72hrs	33.3	50	100	25	50	0	0	0	0	0	0	0	20	50	
	Total	3	2	2	4	2	1	3	3	3	2	1	3	5	2	

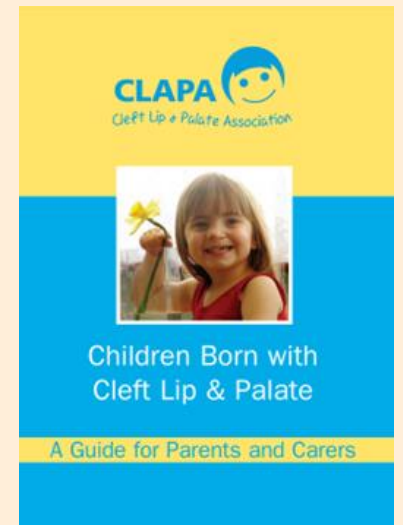# Palate examination: Identification of cleft palate in the newborn - best practice guide update 2025

Retain the 6 recommendations for visual examination, torch & spatula, repeat if not visualised, recording, informing parents, Hospital Trusts responsibilities for training
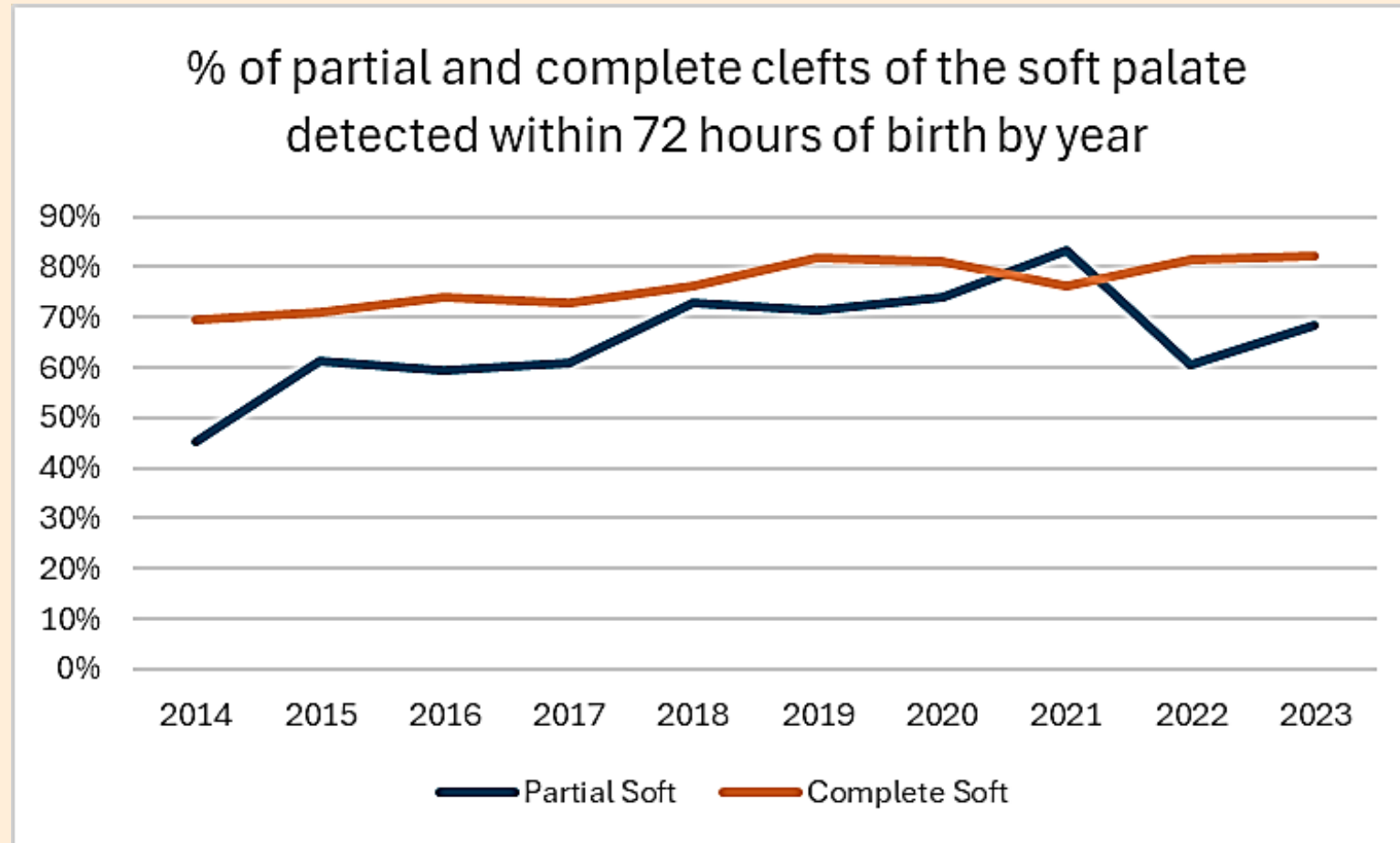
Widening the circle of professionals to educate include 6-8 week check by GP's, also HV's

Patient Information Leaflet replaced by CLAPA
Guide to CLP and NHS Overview of CLP,
plus or minus local centre's leaflets as CNS's advise

CLAPA
Cleft Lip + Palate Association

Children Born with
Cleft Lip & Palate

A Guide for Parents and Carers

CRANE: CPO soft palates 2014-2023
Ahah, a progress marker! Then a stutter in 22-23?

% of partial and complete clefts of the soft palate detected within 72 hours of birth by year

Legend: Partial Soft, Complete Soft

Life size models newborn clefts (2015)

Survey of use of cleft models in GBI
(Cathy Marsh, Alex Habel, in November 2023)

13 centres: 12 responded

4 used monthly

3 used sporadically

Review November 24. In the past 12 months

3 have added the models to their teaching programme

CNS responses to using models

- ***Learners get the message quickly***

- ***Inexperienced students in particular understood…..***

- Had them 10 months now, ***using them every chance I get….***

- Great value ***once it's stressed finger palpation not advised***

- ***Models rarely used, as it's necessary to deter palpation***

- ***Initially feared that using them might lead to using fingers!***

- **CNS share your recent experiences today?**

Hammering down on delayed detection: Lets be Nailing it!

13%

Crane Presentation 2025

Marnie Fullarton

North-West Cleft Network -Liverpool

CRANE

CRANE Date Collection

- Creation of New Baby database-includes all data parameters
- CRANE form to audit clerk simplified
- Louise Hall has access to Crane

Consent

- Entered onto New Baby database –date taken
- Entered into dictated letter if obtained

Reducing late diagnosis

- Cleft Awareness and palate examination
- Education in maternity units
- Education in neonatal units Liverpool & Manchester
- Education in Health Visitor Teams
- Midwifery students Edge Hill and John Moores
- E learning module examination palate RCPCH

Emma Blair, Leeds
Consent

- Achieving 100% consent verification for 2015-2017 births and high positive consent rate (179 eligible children. 178 consented, 1 declined)

    - At this time, paper nursing records were used in Leeds.

    - CRANE information & consent forms were prepared with nursing documentation and available for every patient contact.

    - CRANE discussed in person, the paperwork left with parents to review and complete in their own time and then consent obtained on a subsequent home visit. Consent was obtained early on.

    - Possibly parents at that early stage were still very thankful for information and were keen to give back to service. Seemed to be less anxiety about sharing data during that time.

    - Since our move to electronic documentation, it is not as easy to collect consent quickly.

Emma Blair, Leeds
Early care data completeness & contact with families

- High data completeness rates for early life/care indicators (gestational age, birthweight, diagnosis time, contact time)
  - Nursing documentation is designed to collect all necessary CRANE data.
  - Boxes asking for specific information is more likely to be completed than free text.
  - We have a very good audit coordinator, Rachel Dalton, who prompts us for data ad inputs everything.
- High rate of contact within 24hrs of referral
  - Always prioritised
    - On call weekends and bank holidays
    - Rearrange diaries to accommodate new babies.

CRANE
Making it Better Session

DAVID SAINSBURY

NEWCASTLE CLEFT TEAM

20 JANUARY 2025

Positive Outlier

Consent verification for 2015-2017 births

Data completeness for all 5-year outcomes

Audit Built into Service

- Data Coordinator

- Patients approaching 5 years of age
  - Identified well in advance
  - Brought back to clinic early (e.g. 5 years 1 month)
  - Reinvited if don't attend
  - Clear on clinic list which patients are for audit

- Pre-labelled audit forms are readily available

- Team chased / reminded to complete audit forms

Teamwork

- Team invested in audit process

- Stable, well motivated team

- Good team communication

  - informal

  - formal (twice monthly MDT)

- Audit part of MDT agenda

Thank you

- Any questions?

Achieving High Data Completeness for 5 year growth outcomes and DMFT Scores

CRANE – Making it better – 20th January 2025

Emma Macartney– Lead Nurse for Regional Cleft Services

Denise Scallon – Regional Cleft Co-ordinator

Northern Ireland Regional Cleft Team

Royal Belfast Hospital for Sick Children

BT12 6BE

5y height and weight

- SCN ensures attendance at each 5year clinic
- SCN is on schedule for all patients to see
- SCN completes all heights and weights and asks parent/carer if any other new diagnosis
- SCN inputs all data and checks if 1year outcomes added
- If 1year outcomes are added at under age 1(from 6m) SCN checks with local Child Health Office if child had age 1 health assessment completed by Health Visitor and updates accordingly

(SCN adds preliminary 1year outcomes at Early Intervention clinic which all children with CPO attend from age 6m)

DMFT Scores

- In July Cleft Co-ordinator creates spreadsheet of next year's age 5 patients and starts planning MDT appointments after their 5th birthday in the year ahead

- At MDT Clinic Consultant Dental complete Age 5 Audit CRANE sheet on each child with excellent return rate of DMFTs and DDE scores

- Within following week, Cleft Co-ordinator and Consultant Dentist meet and input CRANE data together to ensure information is accurate when still fresh in Consultant's mind

- On Cleft Co-ordinator spreadsheet, all of patients' DDE, DMFT and overjet measurements are recorded along with details of dental photos and models taken. This is on one view which enables Cleft Co-ordinator to ascertain which patients have been completed and if any awaiting their clinic appointment ensuring therefore they will not breach into 6th birthday

Thank you for listening

Any questions?

Jan 2024 …

+ve outlier	-ve outlier
Dental health	Consent verification
	Child growth
	Facial growth
	Speech reporting
	TIM Psychology
	SDQ Psychology

Improvement Plans

- **Trial & implement 5 year audit clinics**

- **Identify patients suitable for 'audit clinic'**

- **Continued role – governance audit lead**

- **Implement robust SOP for updating consent status**

- **Data coordinator to be appointed**

- **Implementation of new EPR system & plans to update/incorporate database**

Achievements

- **Successfully trialled 5yr audit clinic in February 2024 & 6 further audit clinics in 2024**

- **Use of audit data collection proforma**

- **Combined total for 5yr audit clinics in 2024 (data sets completed for all patients) 73 booked / 69 seen (4 DNAs)**

- **Planned 8 audit clinics for 2025 80 patients**

- **Detailed Consent SOP written – awaiting divisional governance sign off**

- **Consent for 2015-2017 births improved < 60% to almost 80% consent**

- **Data coordinator post written, evaluated and to be advertised this month**

- **EPR May 2024 – in talks with team on how to incorporate data collection**

Future Plans

- Obtain consent status for ALL birth cohorts once consent SOP signed off

- Continue to collect datasets at 5yr audit clinics

- Improve efficiency of 5 year clinics, and enable handover to DC

- Continue to identify missing/incomplete data when inputting 5yr data sets & complete where possible

- Continue to check consent status on outpatient attendance and when submitting dashboard data

- Work with epic team to ensure data needs are met and we have robust systems in place to help achieve this

- DC role fixed term for 12 months – they will lead on crane data collection / missing & incomplete data during this period

South West Cleft Service – CRANE 2024 Annual Report

CHALLENGES FACING THE SW CLEFT SERVICE

Data Items	Score
Consent verification	
Data completeness	
Child growth (weight and height)	--*
Dental health (dmft)	
Facial growth (5-year-old index scores)	--*
Speech (All 16 CAPS-A scores)	--*
Psychology (TIM)	--*
Psychology (SDQ)	--*

2024 Report

Difficulties faced in submission of data to CRANE

- No audit clinics for 2015 births due to covid-19 pandemic.

- Limited number of audit clinics for 2016 and 2017 births. Particular difficulty restarting in peripheral sites (Gloucester, Exeter, Plymouth, Truro).
  - 2016 births : approx. 35% of data collected
  - 2017 births : approx. 70% of data collected
  - 2018 births : approx. 71% of data collected

- Ongoing clinic capacity issues and backlogs, particularly in peripheral sites.

- Unclear responsibilities – data collected but not inputted.

- Clinic cancellations – MDT staff shortages.

Action taken to improve

Following SW Cleft service harm review (2022-2023), funding for a data manager (0.4wte) was allocated as part of large workforce planning package.

Thorough review of audit clinic processes including a review of audit forms.

Development of SOP for the whole MDT to ensure that responsibilities are clear.

Increased number of audit clinics in Bristol and all peripheral sites

Following recommendations from the harm review, we have increased our workforce to support the extra clinic activity.

Next steps

- We recognise that it will take time for improvements to show in CRANE reports given that there were gaps in data collection throughout pandemic and aftermath.
- We hope that workforce expansion and improvements in process will reflect positively through CRANE over the next couple of years.

Q&A

Database developments

Live tables

3. Diagnosis time 2022-24

Number (%) of CRANE-registered children born 2022 to 2024, according to cleft type and the time of diagnosis. ⓘ

| Year / Cleft type | Time of diagnosis in relation to birth | | | | | | | | | | | | | | All |
| | Antenatal | | Within 24 hours | | Within 72 hours | | <= 1 Week | | <= 1 month | | <= 6 months | | > 6 months | | |
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	
⊟ 2022-24	1097	44.4	1052	42.6	118	4.8	68	2.8	66	2.7	51	2.1	17	0.7	2469
└ CL	439	69.6	166	26.3	10	1.6	3	0.5	1	0.2	7	1.1	5	0.8	631
└ CP	9	0.9	739	72.5	105	10.3	57	5.6	61	6	39	3.8	10	1	1020
└ UCLP	430	86.7	65	13.1	0	0	1	0.2	0	0	0	0	0	0	496
└ BCLP	191	88	26	12	0	0	0	0	0	0	0	0	0	0	217
└ Non specified	28	26.7	56	53.3	3	2.9	7	6.7	4	3.8	5	4.8	2	1.9	105
	1097	44.4	1052	42.6	118	4.8	68	2.8	66	2.7	51	2.1	17	0.7	2469

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CRANE
CLEFT REGISTRY & AUDIT NETWORK

Homepage

Request an account

Help/support

System notes

Patient Records

Manage Patient Records

Imports

Live tables

1. Births by region

2. Births by cleft type

3. Diagnosis time 2022-24

4. Consent 2022-24

5. Consent 2016-18

6. Outcomes 2016-18

7. Missing identifiers

8. Transfers

9. Imports

Administration

Account Manager

Created

Modified

Cases by centre

Hospitals

Regions

4. Consent 2022-24

Number (%) of CRANE-registered children born 2022 to 2024, according to region / unit and consent status. (No exclusions applied). ℹ

Region / Unit	Consent status								All
	Consent status verified				Consent status not verified				
	Consented	%	Declined	%	Awaiting verification	%	Not possible to verify	%	
⊟ Northern & Yorkshire	202	71.9	16	5.7	53	18.9	10	3.6	281
└ Leeds	93	72.1	5	3.9	24	18.6	7	5.4	129
└ Newcastle	109	71.7	11	7.2	29	19.1	3	2	152
⊟ North West & North Wales	290	95.7	7	2.3	3	1	3	1	303
└ Liverpool	143	96	4	2.7	1	0.7	1	0.7	149
└ Manchester	147	95.5	3	1.9	2	1.3	2	1.3	154
⊞ Trent	217	90	2	0.8	20	8.3	2	0.8	241
⊞ West Midlands	173	64.6	2	0.7	89	33.2	4	1.5	268
⊞ East	130	76.9	2	1.2	36	21.3	1	0.6	169
⊟ North Thames	281	92.4	4	1.3	16	5.3	3	1	304
└ Chelmsford	71	80.7	2	2.3	15	17	0	0	88
└ Great Ormond St	210	97.2	2	0.9	1	0.5	3	1.4	216
⊟ The Spires	184	79.7	2	0.9	45	19.5	0	0	231
└ Oxford	102	82.9	1	0.8	20	16.3	0	0	123
└ Salisbury	82	75.9	1	0.9	25	23.1	0	0	108
⊟ South Wales & South West	210	86.4	8	3.3	23	9.5	2	0.8	243
└ Bristol	130	84.4	7	4.5	15	9.7	2	1.3	154
└ Swansea	80	89.9	1	1.1	8	9	0	0	89
⊞ South Thames	184	65.9	11	3.9	81	29	3	1.1	279
⊞ Northern Ireland	62	70.5	7	8	17	19.3	2	2.3	88
⊞ Scotland	123	100	0	0	0	0	0	0	123
	2056	81.3	61	2.4	383	15.1	30	1.2	2530

5. Consent 2016-18

Number (%) of CRANE-registered children born 2016 to 2018, according to region / unit and consent status. (No exclusions applied). 🛈

Region / Unit	Consent status								All
	Consent status verified				Consent status not verified				
	Consented	%	Declined	%	Awaiting verification	%	Not possible to verify	%	
⊟ Northern & Yorkshire	357	94.9	11	2.9	0	0	8	2.1	376
└ Leeds	199	98	2	1	0	0	2	1	203
└ Newcastle	158	91.3	9	5.2	0	0	6	3.5	173
⊟ North West & North Wales	400	89.3	12	2.7	20	4.5	16	3.6	448
└ Liverpool	204	91.5	8	3.6	5	2.2	6	2.7	223
└ Manchester	196	87.1	4	1.8	15	6.7	10	4.4	225
⊟ Trent	262	87	2	0.7	34	11.3	3	1	301
└ Nottingham	262	87	2	0.7	34	11.3	3	1	301
⊞ West Midlands	325	80.2	18	4.4	55	13.6	7	1.7	405
⊞ East	182	86.7	2	1	18	8.6	8	3.8	210
⊟ North Thames	332	83.8	9	2.3	49	12.4	6	1.5	396
└ Chelmsford	120	89.6	4	3	8	6	2	1.5	134
└ Great Ormond St	212	80.9	5	1.9	41	15.6	4	1.5	262
⊟ The Spires	233	84.7	3	1.1	39	14.2	0	0	275
└ Oxford	117	86.7	0	0	18	13.3	0	0	135
└ Salisbury	116	82.9	3	2.1	21	15	0	0	140
⊟ South Wales & South West	267	91.1	3	1	12	4.1	11	3.8	293
└ Bristol	168	91.3	3	1.6	9	4.9	4	2.2	184
└ Swansea	99	90.8	0	0	3	2.8	7	6.4	109
⊞ South Thames	309	84.9	18	4.9	22	6	15	4.1	364
⊞ Northern Ireland	103	89.6	1	0.9	4	3.5	7	6.1	115
⊞ Scotland	111	99.1	0	0	0	0	1	0.9	112
	2881	87.4	79	2.4	253	7.7	82	2.5	3295

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6. Outcomes 2016-18

Number (%) of CRANE-consented children born 2016 to 2018 with reported outcomes at five years of age
(excluding children who died before the age of 5 years and children with submucous cleft palate), according to region / unit. ⓘ

Region / Unit	5-year outcomes																	
	Weight			Height		dmft			5 year index			Speech			Psychology		
	Eligible n	Reported n	%	Reported n	%	Eligible n	Reported n	%	Eligible n	Reported n	%	Eligible n	Reported n	%	Eligible n	Reported n	%
⊟ Northern & Yorkshire	338	260	76.9	258	76.3	338	264	78.1	68	38	55.9	215	152	70.7	338	272	80.5
└ Newcastle	153	121	79.1	119	77.8	153	130	85	26	22	84.6	95	74	77.9	153	135	88.2
└ Leeds	185	139	75.1	139	75.1	185	134	72.4	42	16	38.1	120	78	65	185	137	74.1
⊟ North West & North Wales	389	317	81.5	313	80.5	389	335	86.1	77	41	53.2	249	148	59.4	389	255	65.6
└ Liverpool	198														198	119	60.1
└ Manchester	191														191	136	71.2
⊟ Trent	256														256	80	31.3
└ Nottingham	256														256	80	31.3
⊞ West Midlands	322														322	79	24.5
⊞ East	181														181	92	50.8
⊟ North Thames	316														316	175	55.4
└ Great Ormond St	203														203	119	58.6
└ Chelmsford	113														113	56	49.6
⊟ The Spires	229														229	161	70.3
└ Oxford	115														115	72	62.6
└ Salisbury	114														114	89	78.1
⊟ South Wales & South West	261														261	192	73.6
└ Swansea	98	89	90.8	88	89.8	98	81	82.7	17	9	52.9	69	33	47.8	98	89	90.8
└ Bristol	163	48	29.4	48	29.4	163	123	75.5	26	12	46.2	106	52	49.1	163	103	63.2
⊞ South Thames	307	75	24.4	75	24.4	307	143	46.6	56	20	35.7	191	106	55.5	307	130	42.3
⊞ Northern Ireland	81	60	74.1	59	72.8	81	62	76.5	16	4	25	47	21	44.7	81	43	53.1
⊞ Scotland	110	24	21.8	24	21.8	110	81	73.6	18	14	77.8	73	53	72.6	110	96	87.3
	2790	1433	51.4	1423	51	2790	1583	56.7	495	207	41.8	1827	1034	56.6	2790	1575	56.5

Outcomes

Excluded from all 5-year outcomes:
1. Children who died before the age of 5 years.
2. Children with a submucous cleft palate.

Outcome specific inclusions:
5 year old index: eligible for children with a complete UCLP only.

Speech: eligible for non-syndromic children with CP, UCLP and BCLP only.
Children with anomalies affecting the circulatory system or nervous system only,
which do not occur as part of a syndrome, are currently included in speech reporting.

Note that Psychology data reflect children with TIM scores.

Missing identifiers: Linkage and risk adjustment

7. Missing identifiers

Percentage of CRANE-consented children with missing patient identifiers on the CRANE Database, according to unit and year of birth. 🛈

Region / Unit	Missing identifiers							
	NHS/CHI number %		Sex %		Postcode %		> 1 identifier %	
	2000-23	2024	2000-23	2024	2000-23	2024	2000-23	2024
⊞ Northern & Yorkshire	0.3	0	0.2	0	0	5.1	0	0
⊞ North West & North Wales	0	0	0.2	3.2	0	1.1	0	0
⊞ Trent	0.5	0	1.4	0	0.2	0	0.2	0
⊞ West Midlands	0.9	0	0.8	0	25.8	100	0.4	0
⊞ East	2.7	0	0.6	0	9	12.9	0.4	0
⊞ North Thames	1.5	0	0.9	0	4.1	0	0.7	0
⊞ The Spires	1.2	0	0.3	0	2.8	30.4	0.1	0
⊞ South Wales & South West	0.9	7.7	0.7	0	0.6	0	0.2	0
⊞ South Thames	1.5	0	0.2	0	0.2	2.1	0.1	0
⊞ Northern Ireland	28.5	0	0.2	0	1.8	10	1.2	0
⊞ Scotland	0	0	0	0	0.4	0	0	0
	2	0.9	0.5	0.6	4.2	13.9	0.3	0

Service-led registrations

- Database supplier is developing the system to allow Service-led registrations and approvals for CRANE Database access

- Cleft team member with existing access can request access for another Cleft team member by completing form on the database.

- Key people (e.g. Clinical Lead, Service Co-ordinator) will be notified automatically and they can approve the request.

- Access will be granted and username/pw sent to colleague.

- CRANE will be notified by email so records can be updated.

CRANE updates

- No preliminary report (replaced with webinar for CD/CLs – likely to be May '25)
  - Staff/resource changes
  - Live tables provide up to date consent and data completeness rates for indicators subject to outlier policy
  - Data exports allow gaps in registry data to be identified
  - Outlier process allows early sight (August) of funnel plots and supplementary tables
- Introduction of risk adjustment to some outcomes (speech, dental)
- Formal introduction of outlier policy

Key dates

- Q& A webinar: **Wednesday 5 February 2025**, 10:30-12:00
- Organisational audit: **February 2025**
- Dashboard Q3 24/25: **Friday 14 March 2025**
- CD/CL webinar: **May 2025** (Date to be confirmed)
- Annual Report Extract taken: **Sunday 29 June 2025**
- Dashboard Q4 24/25: **Friday 20 June 2025**
- Outlier policy letters sent to Clinical Directors: **August 2025**

Alert

- Please remember when contacting CRANE about a patient
  - **Only use CRANE ID**
  - Never send patient identifiable information to our contact us page or via email:
    - NAME
    - DOB
    - HOSPITAL NUMBER

Thank you